# Finding God Without Words: A Guide to Pastoral Care for Persons with Aphasia

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It happened the day I started my first job as a social worker. I had just earned my master's degree in social work and was looking forward to applying my studies to a practical setting. But suddenly that morning I suffered a brain aneurysm that led to aphasia. My life changed dramatically.

Aphasia is caused by damage to the language areas of the brain, often due to a stroke. It is a relatively common condition, one that affects more than one million Americans. People with aphasia may have trouble putting their thoughts into words (expressive aphasia) and/or understanding the words of others (receptive aphasia). A person with aphasia may feel as though his or her thoughts are on the tip of the tongue but cannot think of the words to express them. Or it may seem that the person they are speaking with is talking in a different language. Aphasia does not diminish a person's intellect, but inhibits their communication.

My aphasia was devastating. I could no longer communicate with others. I felt isolated, depressed, and angry. No one around me seemed to understand what was happening, not even many of the nurses at the hospital. It took enormous energy to sort out even the simplest of phrases and construct a response. That was 30 years ago. Since then I've made some progress, but, like most persons with aphasia, I will probably never regain my full ability to communicate. I still live with frustration and isolation every day. Many persons with aphasia find the stress of their condition overpowering and succumb to depression or even suicide.

Some persons struggling with aphasia have found that they cannot turn to the church for consolation. In fact, church often becomes a negative place for them. The sermon, as well as much of the rest of the service, is incomprehensible. Sunday school becomes a trial that only increases their sense of isolation. The worst is that no one in the congregation seems to understand. Often people will avoid persons with aphasia because it takes so much energy to converse with them. They just give up trying to engage them in conversation.

Neither do most people understand the nature of aphasia. A friend of mine was approached by a member of her congregation who asked her if she could still do housework with her condition. She was hurt, because she felt that housework was one of the things she could still do. People don't understand that aphasia does not affect one's ability to think or to do other activities, but only to communicate with words. Because of avoidance and misunderstanding, church is often such a negative experience for persons with aphasia that their caregivers may discourage them from attending at all.

How can church leaders and church members be sensitive to persons with aphasia who may be in their midst? How can they reach out to those who do not feel comfortable enough to come to worship? I've identified

five ways pastors can be more supportive to persons with aphasia and help them to experience God through their interactions.

1. *Encourage their interest in music and visual arts.*

In the weeks following my stroke, I struggled to relearn how to speak. Even simple phrases like "I'm thirsty" were difficult to articulate. I was making only slow and painful progress when my speech therapist advised me to try singing the phrase. Suddenly the words "I'm thirsty" flowed out of me! Through music, I made steady progress.

When I returned to church, I again felt isolated when I couldn't understand the sermon. But one thing I could understand was the music. I began to attend the church choir practices and found that listening to and participating in the music helped me to reconnect spiritually in a way that I could no longer do through words. I found that I could still sing the old hymns. When we sang new songs, I might have to sing "la la la" instead of articulating the words. Since music is developed in a different part of the brain, I had no problem singing a melody.

Churches that have persons with aphasia in their midst may try to incorporate more musical and visual elements into the service. Recently a professor at a seminary nearby organized a worship service made up only of visual and musical elements. This service was very meaningful for me, of course, but it was also well received by those who did not have aphasia. Visual and musical elements can be appreciated by all members of the congregation and might help to draw persons with aphasia into worship.

2. *Take time to talk with persons with aphasia.*

Conversations will take longer when a person has to sort through every word that is spoken. But instead of becoming impatient, allow yourself time for the interaction. Edith, a friend of mine, has aphasia. She was initially depressed, especially when people avoided talking to her. One day, however, she was walking out of a bookstore and was greeted by an Amish woman. Edith fumbled for words to respond to this woman. Unlike many others, the Amish woman did not try to finish Edith's sentences for her or exhibit any impatience with the speed of her response. Instead, she simply waited for Edith to find her words. When Edith had finally managed a short response, the Amish woman asked another question and again waited for her to respond. When Edith got home, she told her husband about this with tears of joy in her eyes. For the first time in weeks, she felt whole.

Pastors might apply this lesson, of course, during pastoral visits by talking in an unhurried manner and being supportive while persons with aphasia take time to construct a response. It's often tempting to talk only with other people who are in the same household, talking about the person with aphasia rather than to him or her. Pastors might also make sure that persons with aphasia do not fall through the cracks on Sunday mornings by designating two or three people who are willing to check up on these individuals every week and have short conversations. These small practices would mean a lot to those who are ignored much of the time.

3. *Help persons with aphasia realize their own limitations.*

The truth is that very few persons with aphasia will ever fully regain their capacity to communicate. Only rarely do people with aphasia fully heal. With therapy, persons with aphasia can make significant progress. For instance, after 30 years I have moved from a beginning vocabulary of 10 words to being able to speak at public events. But I still have trouble with verbs and sometimes mix up prepositions or pronouns. I still cannot follow

the sermon in church.

Some persons with aphasia may attempt to ignore their condition. Often in a family setting a person with aphasia may try to fill old roles. In one case, a woman with aphasia was used to playing the role of matriarch in her family. She tried to take control in planning family gatherings and in communicating these plans to the family. This caused a lot of frustration because she would either wrongly hear or wrongly communicate the information. While it is important for the family to respect a family member with aphasia and to keep them engaged in family life, it is also true that a person with aphasia must recognize his or her limitations and the necessity for a different lifestyle. It may be important, then, for a pastor to encourage persons with aphasia to set realistic goals. Their lives will not be the same. Every completed conversation is a triumph.

4. *Connect persons with aphasia to available resources.*

Support groups are essential for the wellness of a person with aphasia and his or her caregivers. In a world where people often do not understand their condition, it is a relief to talk among people who struggle with the same things they do. In my community, an aphasia support group meets at the hospital once a month to talk to each other about our experiences. We share our frustrations and our triumphs and enjoy the company of people who understand when we cannot find words right away. Isolation is one of the hallmarks of aphasia, but the support group provides a time of empathy and connection that can sustain persons with aphasia through the interim.

Although it may not be necessary for pastors to be actively involved in such support groups, they might help to locate a support group in the area and encourage the person with aphasia to attend meetings. If no such support group exists, pastors might even help to gather local persons with aphasia and their caregivers together to form a group.

The National Aphasia Association can assist pastors in locating such support groups and providing more information about aphasia. At its website, www.aphasia.org, the NAA provides lists of support groups in the United States and Canada, research updates on relevant topics, and other educational resources.

5. *Treat persons with aphasia as individuals.*

It can be easy to see persons with aphasia only in terms of their condition. Especially since persons with aphasia cannot communicate easily, it is common to overlook their individual personalities. However, all advice on pastoral care for persons with aphasia must be tempered with the caution to treat each case individually. Some persons with aphasia, for instance, will not be interested in singing in the choir or are not musicians. Some persons with aphasia are more introverted than others and will want more or less conversation. To treat any person with dignity is to treat him or her as an individual, and this applies to persons with aphasia as well.

Aphasia is an isolating and frustrating condition, but it can be softened by a caring church community and good pastoral care. Pastors especially should be aware of aphasia and its emotional ramifications. They must seek to assuage the pain of solitude by reaching out to persons with aphasia and incorporating them into the church community. They must exhibit patience and a willingness to relate to these individuals. For persons with aphasia, these practices can transform the church from another isolating experience among many to a place of redemption and communion. ℳ